

Attention deficit hyperactivity disorder (update)

**[G] Evidence reviews for Adherence to treatment
(pharmacological and non-pharmacological)**

NICE guideline CG72

Evidence review

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Draft for Consultation

*This evidence review was developed by
the National Guideline Centre*

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1 Adherence to treatment (pharmacological and non-pharmacological)

1.1 Review question: What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?

1.2 Introduction

Supporting adherence to treatment in people with ADHD has unique challenges. Non-adherence has been conceptualised as falling into two categories – intentional and unintentional (see NICE’s guideline on medicines adherence). Intentional non-adherence occurs when someone makes a decision not to follow the treatment recommendations and unintentional adherence happens when the individual is willing to follow an agreed treatment, but obstacles and problems beyond their control stop them from doing so. Non-adherence should not be seen as the person’s problem. It represents a fundamental limitation in the delivery of healthcare, often because of a failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on. Given the difficulties people with ADHD may have with forgetfulness in everyday activities or in relation to organising tasks, they may be particularly prone to non-adherence of the non-intentional type. For example, they may plan to take their medication but forget to do so, or forget to fill the prescription, or lose the prescription in the interim between receiving it from their doctor and taking it to the chemist. In the case of non-pharmacological treatments they may forget when the appointment is or get distracted on the way to the session. The presence of co-existing mental health or neurodevelopmental conditions may also impact adherence.

The key principles of medicine management are well established and set out clearly in the NICE guideline on medicines adherence. These include ensuring people are involved in discussions about treatment and can make informed decisions about their care. While there are universal principles of care it is important that practitioners are aware of ways to support people with ADHD to be adherent to treatment plans and this chapter considers the factors that people with ADHD believe influence their adherence to both pharmacological and non-pharmacological treatment for their condition.

This review should be read alongside evidence report H on managing treatment and evidence report B on information and support.

1.3 Characteristics table

For full details see the review protocol in appendix A.

Table 1: Characteristics of review question

Objective	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
Population and setting	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers.
Context	Any themes that emerge relating to the adherence of treatment for people with ADHD
Review strategy	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient

qualitative evidence is identified

1.4 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual.¹⁴² Methods specific to this review question are described in the review protocol in appendix A.

Declarations of interest were recorded according to NICE's 2014 conflicts of interest policy.

1.5 Qualitative evidence

1.5.1 Included studies

Fifteen qualitative studies were included in the review; Ahmed 2013¹; Brinkman 2008¹⁴; Charach 2006²⁷; Charach 2014²⁹; Coletti 2012³⁴; Gallichan 2008⁶⁰; Ibrahim 2016⁸⁸; Lefler 2016¹¹¹; Matheson 2013¹²⁵; Meaux 2006¹³³; Meaux 2009¹³²; Mills 2011¹³⁵; O'Callaghan 2014¹⁴⁴; Sikirica 2014¹⁶⁴; Swift 2013¹⁷⁸ these are summarised in Table 2 below. Key themes from these studies are summarised in Section 1.5.2 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix G.

1.5.2 Excluded studies

See the excluded studies list in appendix G.

1.5.3 Summary of qualitative studies included in the evidence review

Table 2: Summary of studies included in the review (pharmacological adherence)

Study	Design	Population	Research aim	Setting
Ahmed 2013 ¹	Focus groups and a framework method of analysis.	16 parents of children with ADHD (aged 3 to 12 years)	To explore factors influencing parents' decisions to adhere and persists with ADHD medication	Australia
Brinkman 2008 ¹⁴	Focus groups with open-ended questions and grounded theory analysis.	52 parents of children with ADHD (aged 6 to 17 years)	To explore how parents make decisions about treatment for their children with ADHD	USA
Charach 2006 ²⁷	Semi-structured focus groups and thematic analysis.	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)	To explore parents' attitudes towards medicating their child	Canada
Charach 2014 ²⁹	Semi-structured interviews and interpretive interactionist framework analysis	12 children with ADHD (aged 12 to 15 years)	Exploring young people's and parents' attitudes towards stimulant treatment	Canada
Coletti 2012 ³⁴	Semi-structured	27 parents of	To explore parent	USA

Study	Design	Population	Research aim	Setting
	focus groups and an inductive approach to analysis, using grounded theory.	children diagnosed with ADHD (aged 5 to 12 years)	perspectives on the decision to initiate medication treatment for ADHD	
Gallichan 2008 ⁶⁰	Open-ended interviews and grounded theory analysis.	12 young people with ADHD (aged 10 to 17 years)	Explore young peoples' perspectives of ADHD	UK
Ibrahim 2016 ⁸⁸	Semi-structured interviews and grounded theory analysis.	8 GPs, 8 consultants, 5 teachers and 5 mothers (of children and young people, age not specified)	Examine the experiences of drug holidays from caregivers and healthcare professionals	UK
Lefler 2016 ¹¹¹	Semi-structured focus groups and idiographic inductive analysis.	36 college students with ADHD (aged >18 years)	To explore the experiences of college students living with ADHD	USA
Matheson 2013 ¹²⁵	Semi structured interviews and thematic analysis.	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)	Explore adults experiences with ADHD	UK
Meaux 2006 ¹³³ (Meaux 2009 ¹³²)	Semi-structured interviews and content analysis.	15 college students with ADHD (aged >18 years)	To gain insight about medication use among young people with ADHD	USA
Mills 2011 ¹³⁵	Semi-structured interviews and constant comparative analysis	19 families (representing 30 children with ADHD) (aged not specified)	To understand how parents decide to medicate their child	USA
O'Callaghan 2014 ¹⁴⁴	Semi-structured telephone interviews and thematic analysis.	18 adults with ADHD	To explore the context that influences stimulant medication adherence	USA
Sikirica 2014 ¹⁶⁴	Telephone interviews and thematic analysis.	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years)	To explore the unmet needs of young people with ADHD and their caregivers	Mixed European countries (including UK)
Swift 2013 ¹⁷⁸	Semi-structured interviews and thematic analysis.	10 young adults with ADHD (aged 17-18)	Patient experiences of ADHD, particularly around transitioning	UK

Study	Design	Population	Research aim	Setting
			services	

1 **Table 3: Summary of studies included in the review (non-pharmacological adherence)**

Study	Design	Population	Research aim	Setting
Smith 2014 ¹⁷¹	Semi-structured focus groups and thematic analysis.	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (aged Pre-schoolers). Parents were all undertaking group parent training	Understanding the reasons of low uptake and completion of parent interventions for ADHD	UK

2 See appendix D for full evidence tables.

3 1.5.4 Qualitative evidence synthesis

4 **Table 4: Review themes**

Main themes	Statement of theme
Understanding drug efficacy	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it
Perceived benefit/lack of benefit	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms.
Side effects	Side effects of medication were described as main reasons for not adhering to it.
Loss of identity	People reported that they didn't feel like themselves whilst on medication
Forgetting to take medication and time management	People with ADHD have difficulty remembering to take their medication and organising appointments.
Willingness to take medication	Children hide their medication from parents, or refuse to take it
Patient self-management	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.
Parental self-management	Parents reduce their child's dosage or have drug holidays without consulting healthcare professionals.
Difficulty accessing prescriptions	Adults report being unable to access treatment due to GPs or pharmacists refusing prescriptions.
Discontinuation when transitioning to adult services	Adults report long periods of treatment cessation when they are transferred to adult services
Barriers to treatments (non-pharmacological)	There are a range of psychological, situational and socioeconomic barriers to non-pharmacological treatment

1 1.5.4.1 Narrative summary of review themes

2 Review theme 1: Understanding drug efficacy

3 Young people felt that as they got older, they realised that their treatment was effective and
4 useful for them. When they were younger, they made attempts to not take their medication,
5 such as hiding their pills or refusing to take them. They gradually learned why they needed to
6 take their medication, and so they adhered more to it as they got older.

7 Explanation of quality assessment: minor methodological limitations in the contributing
8 studies; moderate concerns about coherence of the theme with review theme 7 showing
9 conflicting results (patients making their own treatment plans without consulting healthcare
10 professionals); partial concerns about applicability with one study being conducted in
11 Canada, and the other in the UK; Moderate concerns about adequacy as data was not
12 detailed. There was a judgement of moderate confidence in this theme due to the concerns
13 regarding the applicability of the data and the adequacy

14 Review theme 2a: Perceived benefit/lack of benefit (pharmacological treatment)

15 People on medication are more likely to adhere to their medication if they perceive it to be
16 improving their symptoms. Parents are more likely to consistently adhere to treatment if they
17 feel the improvements extend beyond ADHD symptoms, to functional improvements for all
18 areas of their child's life, such as mood, sleep and social functioning. Adherence is also
19 better when improvements from the medication outweighed side effect; when side effects are
20 worse, this can lead to a lack of adherence. Young people also stop taking their medication if
21 they don't feel like it is helping them.

22 Explanation of quality assessment: minor methodological limitations in the contributing
23 studies; no concerns about coherence of the theme; partial concerns about applicability with
24 only 2/6 studies conducted in the UK; no concerns about adequacy. There was a judgement
25 of moderate confidence in this theme due to the concerns regarding the applicability of the
26 data and the adequacy

27 Review theme 2b: Perceived benefit/lack of benefit (non-pharmacological treatment)

28 Parents were more likely to drop out of parent training if they did not see improvement they
29 expected quickly enough. This was combated by setting realistic expectations and in helping
30 parents to see small improvements.

31 Explanation of quality assessment: minor methodological limitations in the contributing
32 studies; no concerns about coherence of the theme; no concerns about applicability;
33 moderate concerns about adequacy due to only one contributing study. There was a
34 judgement of moderate confidence in this theme due to the concerns regarding adequacy of
35 the data

36 Review theme 3: Side effects

37 Adherence to medication is impacted by the level of side effects experienced by people with
38 ADHD. Those that perceive a high level of side effects are less likely to adhere to their
39 medication, especially if side effects are seen to outweigh the benefit gained from symptom
40 improvement.

41 Explanation of quality assessment: minor methodological limitations in the contributing
42 studies; no concerns about coherence of the theme; partial concerns about applicability due
43 to only 1 of the 3 studies being conducted in the UK; minor concerns about adequacy, as
44 data was not rich but had moderate quantity. There was a judgement of moderate confidence
45 in this theme due to the concerns regarding the relevance of the data.

46 Review theme 4: Loss of identity

1 Adherence to medication is affected by a loss of 'sense of self' in young people. They felt
2 that the medication changed their identity by affecting their personality and the way in which
3 they interact with the world around them.

4 Explanation of quality assessment: minor methodological limitations in the contributing
5 studies; no concerns about coherence of the theme; partial concerns about applicability due
6 to one study being conducted in Canada and one in the UK; moderate concerns about
7 adequacy due to only two contributing studies, with limitations around data richness. There
8 was a judgement of low confidence in this theme due to the concerns regarding the
9 relevance and adequacy of the data.

10 **Review theme 5: Forgetting to take medication and time management**

11 People with ADHD do not feel equipped to successfully stick to their treatment plan. They
12 can forget to take their medication, which is a problem that impacts on their adherence to
13 treatment. In addition they feel unable to keep monthly appointments for medication
14 management. Parents often support their child by ensuring they take their medication, and by
15 organising their appointments for them.

16 Explanation of quality assessment: moderate methodological limitations in the contributing
17 studies (many limitations within the studies, such as issues with richness of the data, and
18 details provided about data analysis, data collection, and the role of the researcher. No
19 concerns about coherence of the theme; partial concerns about applicability; minor concerns
20 about adequacy. There was a judgement of low confidence in this theme due to the concerns
21 regarding the methodological limitations of the data and concerns about applicability.

22 **Review theme 6: Willingness to take medication**

23 It can be difficult to give ADHD medication to children. Some children attempt to not take
24 their medication by hiding it from their parents, and actively fight to not take their medication.
25 This can make it difficult for parents to ensure their children adhere to treatment.

26 Explanation of quality assessment: minor methodological limitations in the contributing
27 studies; no concerns about coherence of the theme; partial concerns about applicability (one
28 study conducted in the UK, one in Canada); moderate concerns about adequacy due to only
29 2 contributing studies. There was a judgement of moderate confidence in this theme due to
30 the concerns regarding the adequacy of the data and concerns about applicability.

31 **Review theme 7: Patient self-management**

32 People with ADHD sometimes take their medication at their own direction, without consulting
33 healthcare professionals. They take 'drug holidays' depending on when they feel they need
34 to take their medication, and when they don't. This is mainly for work or education purposes,
35 such as periods of high work-load and exams. Others reduce their dosage or do not take
36 their medication on the weekend because they don't want the effects of the treatment over
37 this time.

38 Explanation of quality assessment: minor methodological limitations in the contributing
39 studies; no concerns about coherence of the theme; partial concerns about applicability (one
40 study in the UK, three in the USA); no concerns about adequacy. There was a judgement of
41 moderate confidence in this theme due to the concerns regarding the applicability of the
42 data.

43 **Review theme 8: Parental self-management**

44 Parents of children and young people with ADHD often felt solely responsible for managing
45 and monitoring their child's medication. Some parents could cope with their children not
46 taking medication out of school hours, and felt it important to do so due to their concerns
47 about side effects and the long-term impacts of medicating their child. Other parents felt

1 unequipped to do this and so their children were more likely to fully adhere to treatment.
2 Parents also modify dosages or utilising drug holidays of medication when they are concerns
3 about side effects. Although some parents consulted healthcare professionals before doing
4 so, others did not.

5 Explanation of quality assessment: minor methodological limitations in the contributing
6 studies; no concerns about coherence of the theme; partial concerns about applicability (two
7 studies in the UK, two in Australia and one in mixed countries); no concerns about adequacy.
8 There was a judgement of moderate confidence in this theme due to the concerns regarding
9 the applicability of the data.

10 **Review theme 9: Difficulty accessing prescriptions**

11 Adults with ADHD reported healthcare professionals and pharmacists as barriers to their
12 treatment. They sometimes reported difficulty in accessing repeat prescriptions due to
13 pharmacists being unwilling to dispense the treatment, or GPs being unwilling to prescribe
14 medication. These sometimes cause long periods of treatment cessation, lasting from days
15 to years, which is highly distressing for patients.

16 Explanation of quality assessment: moderate methodological limitations in the contributing
17 studies; no concerns about coherence of the theme; minor concerns about applicability; no
18 concerns about adequacy. There was a judgement of moderate confidence in this theme due
19 to the concerns regarding methodological limitations.

20 **Review theme 10: discontinuation when transitioning to adult services**

21 People with ADHD reported long delays in transitions to adult services from child services.
22 This sometimes resulted in discontinuation of support and as a result caused periods of
23 treatment cessation.

24 Explanation of quality assessment: minor methodological limitations in the contributing
25 studies; no concerns about coherence of the theme; no concerns about applicability;
26 moderate concerns about adequacy (only one contributing study). There was a judgement of
27 low confidence in this theme due to the concerns regarding adequacy of the data.

28 **Review theme 11: barriers to adhering to services (non-pharmacological)**

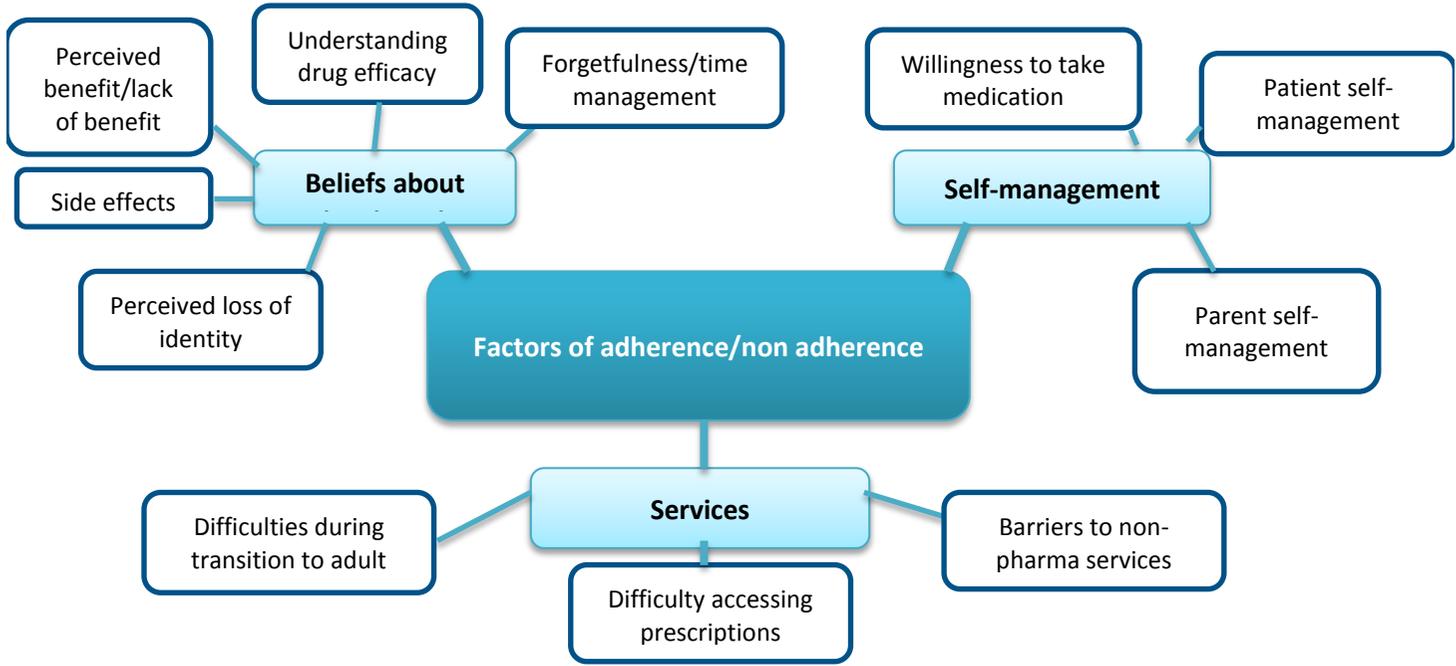
29 Many barriers for patients in accessing non-pharmacological treatment exist. Psychological
30 barriers included feelings of shame, embarrassment and fear of being judged. Situational
31 barriers included time commitments, inconvenient session times and location and child care
32 issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and
33 financial difficulties impacted on adherence.

34 Explanation of quality assessment: minor methodological limitations in the contributing study;
35 no concerns about coherence of the theme; moderate concerns over applicability due to
36 study being based only on group parent training interventions; moderate concerns about
37 adequacy due to only one contributing study. There was a judgement of low confidence in
38 this theme due to the concerns regarding adequacy of the data and applicability.

39

40

Figure 1: Diagram of review themes



1 **1.5.5 Qualitative evidence summary**

2 **1.5.5.1 Theme 1: Psychological factors**

3 **Table 5: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 1: understanding drug efficacy (young people)					
2	2 interviews (1 UK; 1 Canada)	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it	Limitations	minor limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	Moderate concerns about adequacy	

4 **Table 6: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 2a: perceived benefit/lack of benefit (pharmacological; all age groups)					

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
5	1 Focus group 4 Interviews (3 USA, 1 UK; 1 Canada) (3 children, 2 young people, 1 adult)	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms. People are less likely to adhere to their medication when they do not perceive a benefit	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	No concerns about adequacy	

Table 7: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 2b: perceived benefit/lack of benefit (non-pharmacological; pre-schoolers; parent training)					
1	Interviews (UK)	Parents were more likely to drop out of parent training if they did not see improvement they expected quickly enough.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 8: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 3: Side effects; all age groups					
3	2 interviews 1 focus group (1 UK; 1 USA; 1 Canada)	Side effects of medication were described as a main reason for not adhering to it.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

Table 9: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 4: Loss of sense of self (young people)					
2	2 interviews (1 UK; 1 Canada)	People reported that they didn't feel like themselves whilst on medication	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 10: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 5: Forgetting to take medication and time management (all age groups)					
4	3 interviews 1 focus group	People with ADHD have difficulty remembering to take their medication and organising appointments.	Limitations	moderate limitations	LOW
			Coherence	no concerns about	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
	(1 UK; 3 USA)			coherence	
			Relevance	Partially applicable	
			Adequacy	minor concerns about adequacy	

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1.5.5.2 Theme 2: Self-management

Table 11: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 6: Willingness to take medication (children)					
2	1 interview 1 focus group (1 UK; 1 Canada)	Children can actively fight to not take their medication, or hide their medication from their parents.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	moderate concerns about adequacy	

Table 12: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 7: patient self-management (young people and adults)					
4	3 interviews 1 focus group (1 UK; 3 USA)	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

Table 13: Summary of evidence

Study design and sample size	Themes	Quality assessment
------------------------------	--------	--------------------

No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 8: Parent self-management (children and young people)					
5	3 interviews 2 focus groups (2 UK; 2 Australia; 1 mixed European countries including the UK)	Parents reduce their child's dosages or utilise drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	no concerns about adequacy	

Table 14: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 9: Difficulty accessing prescriptions (adults)					
3	3 interviews (2 UK; 1 USA)	Adults report being unable to access treatment due to GPs or pharmacists refusing to write prescriptions or dispense medication.	Limitations	moderate limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	minor	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
				concerns about adequacy	

1 **1.5.5.3 Theme 3: Services**

2 **Table 15: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 10: Discontinuation when transitioning to adult services					
1	Interviews (UK)	Adults report long periods of treatment cessation when they are transferred to adult services	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

Table 16: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 11: Barriers to non-pharmacological treatment					
1	Interviews (UK)	Psychological barriers (feelings of shame, embarrassment and fear of being judged) Situational barriers (time commitments, inconvenient session times and location and child care issues) Socioeconomic barriers (lack of education, cultural issues, domestic violence and financial difficulties)	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

1 **1.6 Economic evidence**

2 **1.6.1 Included studies**

3 No relevant health economic studies were identified.

4 **1.6.2 Excluded studies**

5 No health economic studies that were relevant to this question were excluded due to
6 assessment of limited applicability or methodological limitations.

7 See also the health economic study selection flow chart in appendix E

1

2 **1.7 Resource impact**

3 We do not expect recommendations resulting from this review area to have a significant
4 impact on resources.

5 **1.8 Evidence statements**

6 **1.8.1 Clinical evidence statements**

- 7
- See section 1.5.4.1

8 **1.8.2 Health economic evidence statements**

- 9
- No relevant economic evaluations were identified.

10 **1.9 Recommendations**

11 G1. Use this guideline with the NICE guideline on medicines adherence to improve the care
12 for adults with ADHD. The principles also apply to children and young people.

13 G2. Be aware that the symptoms of ADHD may lead to people having difficulty adhering to
14 treatment plans (for example, remembering to order and collect medication).

15 G3. Ensure that people are fully informed of the balance of risks and benefits of any
16 treatment for ADHD and that problems with adherence are not due to misconceptions
17 (for example, tell people that medication does not change personality).

18 G4. Encourage the person with ADHD to use the following strategies to support adherence to
19 treatment:

- 20
- being responsible for their own health, including taking their medication as needed
 - 21 • following clear instructions about how to take the medication in picture or written
22 format, which may include information on dose, duration, side effects, dosage
23 schedule (the instructions should stay with the medication, for example, a sticker on
24 the side of the packet)
 - 25 • using visual reminders to take medication regularly (for example, apps, alarms,
26 clocks, pill dispensers, or notes on calendars or fridges)
 - 27 • taking medication as part of their daily routine (for example, before meals or after
28 brushing teeth)
 - 29 • attending peer support groups (for both the person with ADHD and for the families
30 and carers).

31 G5. Encourage parents and carers to oversee ADHD medication for children and young
32 people.

33 **Supporting families in which a parent has ADHD**

34 G6. Think about the needs of a parent with ADHD, including whether they need extra support
35 with organisational strategies to help a child with ADHD to take their medication as
36 prescribed.

37 **Supporting adherence to non-pharmacological treatments**

1 G7. Support adherence to non-pharmacological treatments (for example, CBT) by discussing
2 the following:

- 3 • the balance of risks and benefits (for example, how the treatment can have a positive
4 effect on ADHD symptoms)
- 5 • the potential barriers to continuing treatment, including:
 - 6 ○ not being sure if it is making any difference
 - 7 ○ the time and organisational skills needed to commit to the treatment
 - 8 ○ the time that might be needed outside of the sessions (for example, to complete
9 homework)
- 10 • strategies to deal with any identified barriers (for example, scheduling sessions to
11 minimise inconvenience or seeking courses with child care provision)
- 12 • a possible effect of treatment being increased self-awareness and the challenging
13 impact this may have on the person and the people around them
- 14 • the importance of long-term adherence beyond the duration of any initial programme
15 (for example, by attending follow-up/refresher support to sustain learned strategies)

16 **1.10 Rationale and impact**

17 **1.10.1 Why the committee made the recommendations**

18 The evidence identified several factors that affect adherence to treatment and these were
19 supported by the committee's own experience.

20 The evidence highlighted time management and forgetfulness as particular issues so the
21 committee made a recommendation that healthcare professionals should be aware that
22 people with ADHD may have problems remembering to order and collect medication. The
23 committee provided examples of how healthcare professionals might encourage people to
24 follow strategies that support adherence (for example, following clear instructions and using
25 visual reminders).

26 A common worry about treatment is that it might change personality and the committee
27 agreed that this could affect adherence to both medication and non-pharmacological
28 treatments. Misconceptions about the effects of treatment and worries about side effects
29 were common themes identified, and the committee agreed that it was important that
30 healthcare professionals address these.

31 Evidence identified the influence people close to a person with ADHD can have on
32 adherence. The committee agreed that it was important that while children and young people
33 should take responsibility for their own health (including taking medication) parents and
34 carers should oversee them. The committee discussed the difficulties in families where
35 parents may also have ADHD and made a recommendation to remind healthcare
36 professionals that these families may need extra support.

37 The committee discussed that adherence to non-pharmacological treatment was an
38 important issue that was rarely addressed. They used their own experience to recommend
39 that healthcare professionals discuss the commitment, time and organisational skills needed
40 for successful adherence to non-pharmacological treatment.

41 **1.10.2 Why we need recommendations on this topic**

42 Supporting adherence to treatment in people with ADHD has unique challenges. Given the
43 difficulties people with ADHD may have with forgetfulness in everyday activities or in relation
44 to organising tasks, they may be particularly prone to non-adherence of the non-intentional
45 type. For example, they may plan to take their medication but forget to do so, or forget to fill

1 the prescription, or lose the prescription between receiving it from their doctor and taking it to
2 the chemist. While the key principles of medicine management are well established and set
3 out clearly in the NICE guideline on medicines adherence it is important that practitioners are
4 aware of ways to support people with ADHD to be adherent to treatment plans and this
5 chapter/ section considers the factors that people with ADHD believe influence their
6 adherence to both pharmacological and non-pharmacological treatment for their condition.

7 **1.10.3 Impact of the recommendations on practice**

8 The committee noted that the recommendations will reinforce current best practice.

9 **1.11 The committee's discussion of the evidence**

10 **1.11.1 Interpreting the evidence**

11 **1.11.1.1 The quality of the evidence**

12 All the evidence was of low to moderate quality. The majority of subthemes had minor
13 methodological limitations in the contributing studies. There were mainly only minor concerns
14 about the coherence of the themes. Many of the studies had moderate concerns about
15 relevance and adequacy. The studies were all conducted in a population of people with
16 ADHD, or in carers or healthcare professionals who supported people with ADHD. For some
17 subthemes, only a small amount of evidence was identified. The majority of studies were
18 conducted within Canada, the USA, Australia and the UK. Although Canada and Australia
19 have similar healthcare systems to the UK, the USA does not. This was taken into account
20 when assessing the applicability of the themes around the delivery of services. The
21 committee were in agreement that the subthemes presented were consistent with their own
22 clinical experiences.

23 **1.11.1.2 Themes identified in the evidence synthesis**

24 The review identified a number of factors that influence adherence to pharmacological
25 treatment in people with ADHD. These included psychological factors, self-management
26 behaviours, and service barriers.

27 The perception of the benefit of treatment and side effects were found to influence
28 adherence. People were found not to adhere to treatment if they did not perceive it to be
29 improving their symptoms. Parents were also more likely to adhere to treatment if they felt
30 the improvements extended beyond ADHD symptoms, to functional improvements for all
31 areas of their child's life, such as mood, sleep and social functioning. In addition, adherence
32 was found to be better when improvements from the medication outweighed side effects;
33 when side effects were worse, this led to a lack of adherence.

34 The committee agreed that healthcare professionals should discuss with children, young
35 people and adults with ADHD and their parents or carers the impact that medication can
36 have on individuals, and how this can be managed. In addition, the committee noted that
37 healthcare professionals should explain the process of achieving an optimal balance
38 between efficacy of treatment and side effects, ways to reduce side effects (with particular
39 emphasis on titration periods), the importance of adherence to treatment, and how parents or
40 carers could help to improve treatment adherence. The committee noted that healthcare
41 professionals should fully disclose possible side effects with people with ADHD and their
42 carers. The committee also agreed that in young people and adults with ADHD, support
43 groups could be a useful way for patients to gain support by discussing experiences with
44 treatment with others. This evidence supported the recommendations made in the
45 management of treatment and information and support sections.

1 The committee noted the importance of providing clear instructions, which should be
2 individualized into the appropriate format for that person. They agreed that in families where
3 parents or carers also have ADHD, healthcare professionals needed to be aware of the
4 needs of parents and how they might require additional support to help their children adhere
5 to treatment.

6 The committee discussed the monitoring of treatment, and agreed that healthcare
7 professionals should endeavour to understand how the medication impacts the patients' life.
8 They felt that in adults with ADHD, it may be useful to have someone else present during
9 conversations.

10 Age was also found to influence adherence. Some people with ADHD began to understand
11 why they needed to take medication as they got older, and so adhered to treatment. For
12 others, they began to take control of their treatment and establish autonomy over decisions
13 to take medication; in some cases only taking their medication when they felt they needed it,
14 such as during times of high workload. The committee agreed that both of these
15 circumstances arise, and they highlighted the importance of recognising young people's
16 increased involvement in medication decision-making.

17 The evidence suggested that people were not adhering to treatment when they felt that it
18 was causing a loss of identity or change in personality. The committee noted that they had
19 often come across this in their own clinical experiences. They discussed the importance of
20 healthcare professionals recognising these concerns, particularly in young people that have
21 an increased autonomy over their medication decisions.

22 The evidence suggests that people with ADHD have difficulty remembering to take their
23 treatment, and difficulty in arranging and organising appointments with healthcare
24 professionals in order to monitor treatment. The committee discussed ways to reduce
25 problems related to forgetting to take medication, such as obtaining batch prescriptions from
26 pharmacies. The committee agreed that healthcare professionals should discuss techniques
27 that could be used to support planning and management of medication taking. They noted
28 that simple drug regimens should be used (for example, once daily modified release doses),
29 in order to aid adherence.

30 The review identified barriers to services that are experienced by adults with ADHD. The
31 evidence suggested that adults could find difficulty in accessing prescriptions, due to
32 uncertainty from healthcare professionals and pharmacists. The committee discussed ways
33 to improve these experiences for people with ADHD. They suggested that healthcare
34 professionals should discuss these issues with people with ADHD. They agreed that people
35 with ADHD providing documentation could help, which could be particularly useful when
36 travelling abroad, as difficulty could arise due to carrying a control drug.

37 The evidence suggested that young adults may be unable to access treatment whilst they
38 are transitioning from paediatric to adult services. The committee noted the importance of a
39 shared care arrangement over primary and secondary care that could be continued at a time
40 young people transition to adult services. They felt that this would improve the confidence of
41 primary healthcare professionals in continuing to prescribe medication.

42 **1.11.2 Cost effectiveness and resource use**

43 No economic evidence was identified on the adherence to treatment in people with ADHD,
44 as this was a qualitative review and therefore did not look at the clinical effectiveness or cost
45 effectiveness of interventions.

46 The recommendations made by the committee are not expected to have any major cost
47 implications as they indicate what elements have to be considered by healthcare
48 professionals in the discussion of treatment with the patients and all interventions that are
49 mentioned are considered to already be best clinical practice. This review aims at changing

1 the content of discussions around treatment, rather than the quantity or intensity of the
2 treatment reviews. Improved treatment adherence would lead to more efficient care and
3 decision making further down the line with the aim of reducing treatment burden and adverse
4 events, which would create some cost savings to the NHS.

5 **1.11.3 Other factors the committee took into account**

6 Based on their experience, the committee discussed what should be discussed between the
7 person with ADHD, the parent or carer, and the healthcare professional. They felt that it
8 should cover managing expectations of treatment and helping patients to understand the
9 benefit and harm of treatment, and the impact on their lives as a whole. Healthcare
10 professionals should relate this information to the importance of adherence to treatment. The
11 titration process should be discussed, with particular emphasis on achieving an optimal
12 balance between the efficacy and side effects of the treatment. The committee also felt that
13 healthcare professionals should discuss with parents or carers issues around children hiding
14 medication, or refusing to take it.

15 The committee also highlighted the importance of good communication and involvement of
16 the child wherever possible, and for this to be appropriate to the developmental level of the
17 child. They also emphasised the importance of individualising this for each patient or family,
18 depending on their care needs. For example, the instructions should be in the appropriate
19 format for that individual. This may be written instructions, instructions using pictures, or
20 could use different methods based on the persons' needs, and appropriate to the
21 development level of the person with ADHD. These discussions were based partly on their
22 experience but also informed by the themes relating to the types of information people
23 preferred. In addition, the committee noted that separate recommendations may be needed
24 for families with ADHD, where the parents also have ADHD, or other behaviour or mental
25 health conditions. Here, parents might need additional support in helping their children in
26 adhering to their medication. This support should be individualised to the needs of both the
27 parent and the child. There may be different communication issues that exist for children and
28 adults, and so the committee felt recommendations should be made separately for each age
29 strata.

30 The committee highlighted that providing immediate information on side effects was
31 important, in order to give patients and their carers advice on what to do and how best to
32 manage these. The committee highlighted that there may not currently be someone identified
33 to do this, and that it is important to identify a specific healthcare professionals that could be
34 contacted, in order to help with the optimization process. The committee highlighted that
35 currently, services were discharging children back to their GPs, and GPs often do not provide
36 the level of information on side effects that patients and their parents or carers require.

37 The committee highlighted that a shared care protocol was required to better equip GPs with
38 the information needed to continue prescribing treatment. The committee noted that a
39 number of the qualitative reviews in this guideline identified situations in which the interface
40 between primary and secondary care was contributing to the variations in care. . The
41 evidence showed that people with ADHD thought secondary services should be involved in
42 distributing shared care plans. The committee felt that GPs had a responsibility of care to
43 prescribe medication to people with ADHD, but had a lack of training or awareness in the
44 area. Currently, some CDCs discharge young people with ADHD back to primary care before
45 they transition to adult services, without full guidance on the treatment requirements
46 necessary for the person with ADHD.

47 The committee highlighted that the needs of children and young people with ADHD could
48 vary greatly, and that monitoring and managing adherence should take this into account.
49 There could be a variety of responses to medication which relates to the child's increased
50 role in decision making. For example sometimes, young people may need to stop their
51 medication to understand the benefits they were receiving from it. The GC highlighted the

1 importance of 'watchful waiting' in these cases. Other children may be known to be lively and
2 socially active. If their medication subdues them, they may be at risk of feeling like their
3 medication has changed them too much to adhere to. The committee emphasised the
4 importance of individualising treatment management and support to each persons' own
5 situation.

6 The committee noted that in their experience shared decision making between the person
7 with ADHD, the parents or carers, and the healthcare professional, could be difficult. Parents
8 find their children's increased involvement difficult and the healthcare professional may find it
9 difficult to determine the level of involvement from both patients and parents. The committee
10 noted there should be clarity of what should be considered for children, young people and
11 adults taking into the account the changing involvement of young people in their treatment.
12 They noted that more involvement in decision making could occur from early on in
13 adolescence and needs to be recognised by healthcare professionals. The committee felt it
14 was important not to overlook the fact that they might need to give young people similar
15 information to that they are giving adults.

16 The committee had concerns that the ADHD population may be more likely to be self-
17 medicating and buying drugs illegally. In addition, they noted that some people with ADHD
18 may be selling their medication and apparent adherence to treatment may be masking that
19 the person with ADHD is selling on their medication. Issues around self-medication and
20 selling of ADHD medication were identified in the review. The committee agreed that this is
21 important for healthcare professionals to be aware of.

22 The committee discussed many ways to help people to remember to take their medication or
23 order their next prescription. They highlighted the importance of clear instructions and the
24 need for them to with the medication. This could be a sticker on the side of the packet, the
25 committee noted that separate pieces of paper given at the same time as the prescription
26 would be likely to be lost or forgotten.

27 Based on their own experience, the committee discussed the use of apps, and medicine
28 boxes that use smart technology that will indicate whether or not you have taken your
29 medication. For example, there are barcode scanning apps that will only allow a phone to be
30 unlocked when the barcode on the medication has been scanned. The committee noted it
31 would be useful to have a system in place to remind patients to reorder their medication
32 when it's almost finished. Pharmacies can also be supportive obtaining repeat prescription
33 from GPs, or access batch prescriptions which will help the person with ADHD to access
34 treatment. They also noted other techniques to help planning, such as the use of dosset
35 boxes so it is easy to tell how long ago the pill bottle was open, pill boxes should be labelled
36 with days of the week. The committee were keen to illustrate the unique difficulties that
37 people with ADHD have in adhering to medication and the story below, brought to the
38 committee's attention by one of the lay members, reflects their experience and underpins the
39 importance of these recommendations,

40 'Every morning the dreaded question: "Did I take my meds already?"

41 It is unavoidable no matter what trick I try to use.

42 This morning however the situation almost took a turn for the worse.

43 I was being my usual self, getting ready, making my lunch while putting on deodorant and
44 checking reddit all at once, you know how it is.

45 Usually I stop when I see my pill bottle and have to wonder whether or not I've taken it, I
46 realize I hadn't and take my medication out of the bottle. I then remember that I needed to
47 give the dog her epilepsy meds as well, so I took her pill out the bottle. I then realized I didn't
48 have the candy things they use to give her her meds, so I turn around to go to the cupboard
49 and get them.

1 I get back to the counter, take a bite of my bagel, try to remember if the deodorant is out
2 because I wanted to put it on or if I had just left it there. Anyways, grab the pill, put it in the
3 candy thing for the dog, give it to the dog.

4 Did I take my meds yet?

5 Look on the counter, all that's there is the tiny epilepsy pill... oh no.

6 Chase the dog, grab the dog, get the stupid candy thing out of her mouth, break it open,
7 there's my pill! Realize I would've killed the dog, get angry at myself, grab another candy
8 thing give her the right pill.

9 Realise I'm gonna miss the bus, grab my lunch, out the door.

10 Get on the bus, wait... did I take my meds?'

11

12

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- 31 193. Williamson P, Koro-Ljungberg ME, Bussing R. Analysis of critical incidents and
32 shifting perspectives: transitions in illness careers among adolescents with ADHD.
33 *Qualitative Health Research*. 2009; 19(3):352-365
- 34 194. Winter H, Moncrieff J, Speed E. "Because you're worth it": A discourse analysis of the
35 gendered rhetoric of the ADHD woman. *Qualitative Research in Psychology*. 2015;
36 12(4):415-434
- 37 195. Wright SF. "A little understood solution to a vaguely defined problem": Parental
38 perceptions of Ritalin. *Educational and Child Psychology*. 1997; 14(1):50-59
- 39 196. Young S, Bramham J, Gray K, Rose E. The experience of receiving a diagnosis and
40 treatment of ADHD in adulthood: a qualitative study of clinically referred patients
41 using interpretative phenomenological analysis. *Journal of Attention Disorders*. 2008;
42 11(4):493-503
- 43 197. Young S, Chesney S, Sperlinger D, Misch P, Collins P. A qualitative study exploring
44 the life-course experiences of young offenders with symptoms and signs of ADHD

- 1 who were detained in a residential care setting. *Criminal Behaviour and Mental*
2 *Health*. 2009; 19(1):54-63
- 3 198. Young S, Gray K, Bramham J. A phenomenological analysis of the experience of
4 receiving a diagnosis and treatment of ADHD in adulthood: a partner's perspective.
5 *Journal of Attention Disorders*. 2009; 12(4):299-307
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7 based intervention for Chinese children with adhd and their parents: A pilot mixed-
8 method study. *Mindfulness*. 2016; Epublication
- 9
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Appendices

Appendix A: Review protocols

Table 17: Review protocol: Adherence to treatment (pharmacological and non-pharmacological)

Field	Content
Review question	What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?
Type of review question	Qualitative
Objective of the review	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
Eligibility criteria – population / disease / condition / issue / domain	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers. Stratify by age (<5 years old, 5 to 18, >18 years old) and treatment (pharmacological; non-pharmacological).
Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Not applicable
Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
Outcomes and prioritisation	Themes will be identified from the papers, and not specified in advance. However relevant themes may include: <ul style="list-style-type: none"> • Self-help tips to improve adherence; for example, use of alarms and reminders, use of technology/apps • Role of parents/partners/carers in promoting adherence • Psychological factors that impact on adherence; for example, self- and social-stigma, beliefs about ADHD and about treatment, comorbid mental health conditions • Dosing schedules, including use of extended release drug preparations
Eligibility criteria – study design	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified
Other inclusion exclusion criteria	Exclusions: ADHD diagnosis made not using DSM-III/ICD-10 or later versions of these (note that studies evaluating treatments for ADHD in a population of people with autistic spectrum disorder will be included if no formal diagnosis of ADHD has been made using these, but evidence of moderate to severe symptoms of hyperactivity, impulsivity, and/or inattention is demonstrated according to validated symptom questionnaires)
Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
Selection process –	No duplicate screening was deemed necessary for this question, for

duplicate screening / selection / analysis	<p>more information please see the separate Methods report for this guideline.</p> <p>Appraisal of methodological quality: The methodological quality of each study will be assessed using NGC checklists.</p> <p>Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings will be reported according to GRADE CERQual standards</p> <p>Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.</p>
Data management (software)	<ul style="list-style-type: none"> • Endnote for bibliography, citations, sifting and reference management
Information sources – databases and dates	<p>Clinical search databases to be used: Medline, Embase, CINAHL, PsycINFO Date: All years</p> <p>Health economics search databases to be used: Medline, Embase, NHSEED, HTA Date: Medline, Embase from 2014 NHSEED, HTA – all years</p> <p>Language: Restrict to English only</p> <p>Supplementary search techniques: backward citation searching</p> <p>Key papers: Not known</p>
Identify if an update	Not an update
Author contacts	https://www.nice.org.uk/guidance/cg72
Highlight if amendment to previous protocol	Not an amendment
Search strategy – for one database	For details please see appendix B
Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables).
Methods for assessing bias at outcome / study level	The risk of bias across all available evidence was evaluated for each outcome according to GRADE CERQual standards.
Criteria for quantitative synthesis	N/A
Methods for quantitative analysis – combining studies and exploring (in)consistency	N/A
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual and the methods section of this guideline.

Rationale / context – what is known	For details please see the introduction to the evidence review.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Gillian Baird in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, critically appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual and the methods section of this guideline.
Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
PROSPERO registration number	Not registered

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Table 18: Health economic review protocol

Review question	All questions – health economic evidence
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocols in appendix A above. Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see appendix B. For questions being updated, the search will be run from December 2007, which was the cut-off date for the searches conducted for NICE guideline CG72
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2001, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Studies published after 2001 that were included in the previous guideline will be reassessed for inclusion and may be included or selectively excluded based on their relevance to the questions covered in this update and whether more applicable evidence is also identified. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in appendix H of Developing NICE guidelines: the manual (2014). ¹⁴² Inclusion and exclusion criteria If a study is rated as both ‘Directly applicable’ and with ‘Minor limitations’ then it will be included in the guideline. A health economic evidence table will be completed and it will

Review question	All questions – health economic evidence
	<p>be included in the health economic evidence profile.</p> <p>If a study is rated as either ‘Not applicable’ or with ‘Very serious limitations’ then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile.</p> <p>If a study is rated as ‘Partially applicable’, with ‘Potentially serious limitations’ or both then there is discretion over whether it should be included.</p> <p>Where there is discretion</p> <p>The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in appendix G.</p> <p>The health economist will be guided by the following hierarchies.</p> <p>Setting:</p> <p>UK NHS (most applicable).</p> <p>OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).</p> <p>OECD countries with predominantly private health insurance systems (for example, Switzerland).</p> <p>Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.</p> <p>Health economic study type:</p> <p>Cost–utility analysis (most applicable).</p> <p>Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis).</p> <p>Comparative cost analysis.</p> <p>Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.</p> <p>Year of analysis:</p> <p>The more recent the study, the more applicable it will be.</p> <p>Studies published in 2001 or later (including any such studies included in the previous guideline) but that depend on unit costs and resource data entirely or predominantly from before 2001 will be rated as ‘Not applicable’.</p> <p>Studies published before 2001 (including any such studies included in the previous guideline) will be excluded before being assessed for applicability and methodological limitations.</p> <p>Quality and relevance of effectiveness data used in the health economic analysis:</p> <p>The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.</p> <p>Economic evaluations that are based on studies excluded from the clinical review will be excluded.</p>

Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual, Oct 2014, updated 2017
<https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869>

For more detailed information, please see the Methodology Review.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 19: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1948 – 28 April 2017	Exclusions Patient views/qualitative studies
Embase (OVID)	1974– 28 April 2017	Exclusions Patient views/qualitative studies
CINAHL (EBSCO)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies
PsycINFO (ProQuest)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies

Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.

18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
30.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
31.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
32.	or/29-31
33.	28 and 32

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Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/

21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
28.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
29.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
30.	or/27-29
31.	26 and 30

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CINAHL (EBSCO) search terms

S1.	(MH "Attention Deficit Hyperactivity Disorder")
S2.	((attenti* or disrupt*) n3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*))
S3.	adhd or addh or ad hd or ad/hd
S4.	attenti* n3 deficit*
S5.	((hyperkin* or hyper kin*) n1 (syndrome* or disorder*)) or hkd)
S6.	(minimal brain n2 (dysfunct* or disorder*))
S7.	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8.	(MH "Qualitative Studies+")
S9.	(MH "Qualitative Validity+")
S10.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S11.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S12.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S13.	S8 OR S9 OR S10 OR S11 OR S12
S14.	S7 AND S13
S15.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S16.	S14 NOT S15 Limiters - English Language; Exclude MEDLINE records

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PsycINFO (ProQuest) search terms

1.	SU.EXACT.EXPLODE("Attention Deficit Disorder") OR TI((attenti* OR disrupt*) NEAR/3 (adolescent* OR adult* OR behav* OR child* OR class OR classes OR classroom* OR condition* OR difficult* OR disorder* OR learn* OR people OR person* OR poor OR problem* OR process* OR youngster*)) OR AB((attenti* OR disrupt*) NEAR/3 disorder*) OR TI,AB(adhd OR addh OR ad-hd OR ad??hd) OR TI,AB(attenti* NEAR/3 deficit*) OR TI,AB(((hyperkin* OR (hyper-kin*)) NEAR/1 (syndrome* OR disorder*)) OR hkd) OR TI,AB(minimal NEAR/1 brain NEAR/2 (dysfunct* OR disorder*))
2.	SU.EXACT("Qualitative Research") OR (SU.EXACT("Narratives") OR SU.EXACT("Interviews")) OR (SU.EXACT("Questionnaires") OR SU.EXACT.EXPLODE("Surveys")) OR (qualitative OR interview*) OR (focus-group* OR theme*) OR (questionnaire* OR survey*) OR (metasynthes* OR meta-synthes*) OR (metasummar* OR meta-summar*) OR (metastud* OR meta-stud*) OR (metathem* OR meta-them*) OR ethno* OR (emic OR etic) OR (phenomenolog* OR "grounded theory") OR (constant-compar* OR thematic* NEAR/3 analys*) OR (theoretical-sampl* OR purposive-sampl*) OR (hermeneutic* OR heidegger*) OR (husserl* OR colaizzi*) OR (van-kaam* OR van-manen*) OR (giorgi* OR glaser*) OR (straus* OR ricoeur*) OR (spiegelberg* OR merleau*)
3.	1 AND 2
4.	NOT (Dissertations & Theses AND Books)
5.	English

2 B.2 Health Economics literature search strategy

3 Health economic evidence was identified by conducting a broad search relating to ADHD
4 population in NHS Economic Evaluation Database (NHS EED – this ceased to be updated
5 after March 2015) and the Health Technology Assessment database (HTA) with no date
6 restrictions. NHS EED and HTA databases are hosted by the Centre for Research and
7 Dissemination (CRD). Additional searches were run on Medline and Embase.

8 **Table 20: Database date parameters and filters used**

Database	Dates searched	Search filter used
Medline	2014 – 28 April 2017	Exclusions Health economics
Embase	2014 – 28 April 2017	Exclusions Health economics
Centre for Research and Dissemination (CRD)	HTA - 2008 – 28 April 2017 NHSEED - 2008 to March 2015	None

9

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Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*).ti,ab.
8.	or/1-7

9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.
18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Economics/
30.	Value of life/
31.	exp "Costs and Cost Analysis"/
32.	exp Economics, Hospital/
33.	exp Economics, Medical/
34.	Economics, Nursing/
35.	Economics, Pharmaceutical/
36.	exp "Fees and Charges"/
37.	exp Budgets/
38.	budget*.ti,ab.
39.	cost*.ti.
40.	(economic* or pharmaco?economic*).ti.
41.	(price* or pricing*).ti,ab.
42.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
43.	(financ* or fee or fees).ti,ab.
44.	(value adj2 (money or monetary)).ti,ab.
45.	or/29-44
46.	exp models, economic/
47.	*Models, Theoretical/
48.	*Models, Organizational/
49.	markov chains/
50.	monte carlo method/
51.	exp Decision Theory/
52.	(markov* or monte carlo).ti,ab.

53.	econom* model*.ti,ab.
54.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
55.	or/46-54
56.	28 and (45 or 55)

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Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/
21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	statistical model/
28.	exp economic aspect/
29.	27 and 28
30.	*theoretical model/
31.	*nonbiological model/
32.	stochastic model/
33.	decision theory/
34.	decision tree/
35.	monte carlo method/
36.	(markov* or monte carlo).ti,ab.

37.	econom* model*.ti,ab.
38.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
39.	or/29-38
40.	*health economics/
41.	exp *economic evaluation/
42.	exp *health care cost/
43.	exp *fee/
44.	budget/
45.	funding/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* or pricing*).ti,ab.
50.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
51.	(financ* or fee or fees).ti,ab.
52.	(value adj2 (money or monetary)).ti,ab.
53.	or/40-52
54.	26 and (39 or 53)

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NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Attention Deficit and Disruptive Behavior Disorders
#2.	MeSH DESCRIPTOR Attention Deficit Disorder with Hyperactivity
#3.	(((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)):TI
#4.	(((attenti* or disrupt*) adj3 disorder*))
#5.	((adhd or addh or ad hd or ad??hd))
#6.	((attenti* adj3 deficit*))
#7.	(((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd))
#8.	((minimal brain adj2 (dysfunct* or disorder*)))
#9.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
#10.	(#9) IN NHSEED, HTA

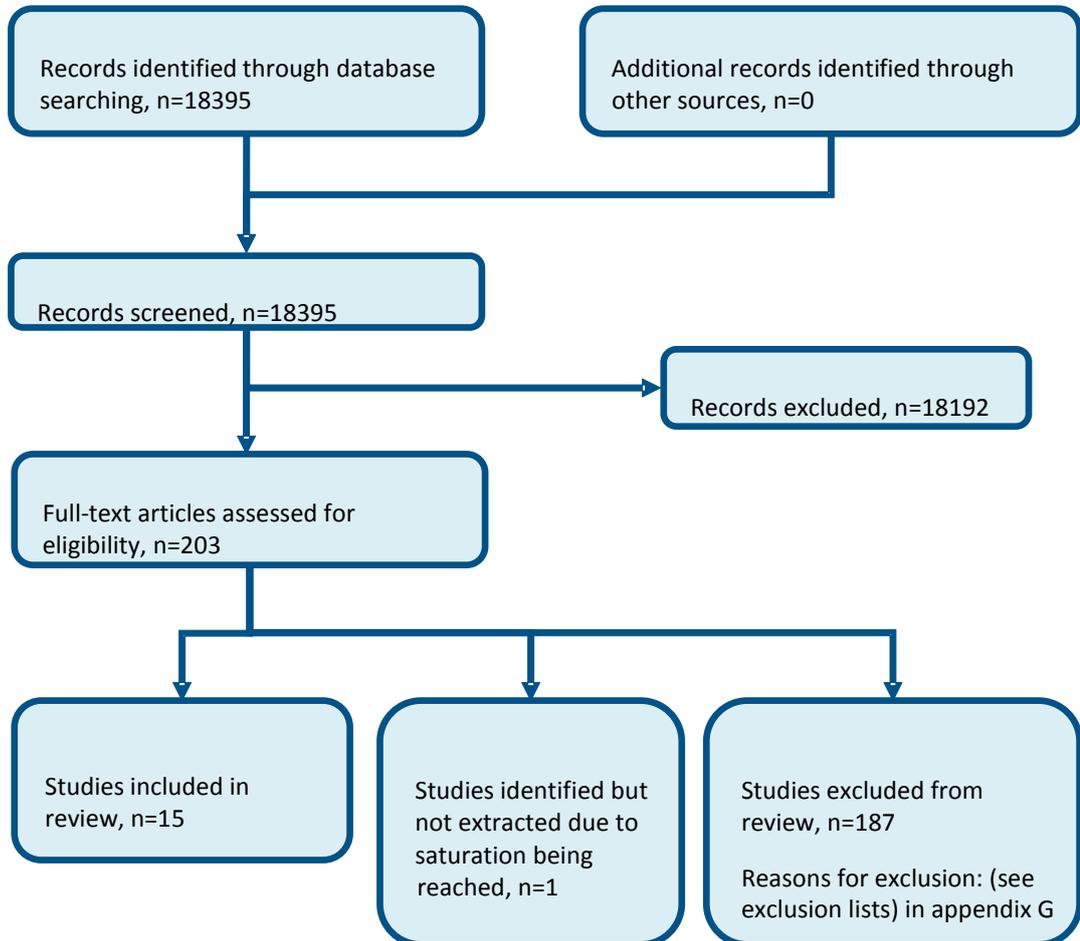
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Appendix C: Qualitative study selection

Figure 2: Flow chart of clinical article selection for the review of adherence



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Appendix D: Qualitative evidence tables

Study (ref id)	Ahmed 2013 ¹
Aim	To explore factors influencing parents' decisions to adhere and persist with ADHD medication
Population	16 parents of children with ADHD (aged 3 to 12 years)
Setting	Australia
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups lasted from 1 to 1.5 hours and were facilitated by a researcher experienced in conducting focus groups. A guide was used to lead discussions. A framework method of analysis was used whereby a thematic framework was developed based on the major themes identified in the dat.
Themes	Parents were concerned about the side effects of medication, and often modified medication doses due to this. Some consulted with HCPs prior to any modifications, whereas others did not. Many parents reported utilising drug holidays to reduce unwanted side effects, without consulting HCPs
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Brinkman 2008 ¹⁴
Aim	To explore how parents make decisions about treatment for their children with ADHD
Population	52 parents of children with ADHD (aged 6 to 17 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	12 focus groups with an average length of 1.5 hours. Prompting questions were developed by all investigators and were broad, open ended initially, followed by more specific probing questions to clarify responses and narrow the discussion. Recruitment was terminated when the investigators felt data saturation had been reached. Grounded theory was used for analysis, whereby the investigators read

Study (ref id)	Brinkman 2008¹⁴
	the transcripts, identified emerging themes, and labelled themes to construct a codebook.
Themes	Parents reported that their children sometimes forgot to take their medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Charach 2006²⁷
Aim	To explore parents' attitudes towards medicating their child
Population	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)
Setting	Canada
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were led by a social worker and a practical nurse specialist who had worked with the families. A semi-structured guide was used; parents were asked to describe their experiences regarding the use of medication. Data was analysed using thematic analysis. Initially analysed by line by line coding, followed by reviewing of these codes by the whole research team. This was followed by clustering codes into themes that best represented the data set.
Themes	An important aspect of this decision-making was the willingness of the child to take medication. Some children actively fought to not take medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Charach 2014²⁹
Aim	Exploring adolescents and parents' attitudes towards stimulant treatment
Population	12 children with ADHD (aged 12 to 15 years)
Setting	Canada
Study design	Interviews
Methods and analysis	Semi structured interviews with interview questions, lasting between 60 to 90 minutes. Transcripts were analysed using interpretive interactionist framework
Themes	Some patients continued to adhere to treatment as they got older, as they realised the efficacy of the medication Children stopped medication due to adverse events, insufficient benefit, feeling that the medication changed their sense of self
Limitations and applicability of evidence	Minor limitations related to the role of the researcher and context of the study

Study (ref id)	Coletti 2012³⁴
Aim	To explore parent perspectives on the decision to initiate medication treatment for ADHD
Population	27 parents of children diagnosed with ADHD (aged 5 to 12 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were 2 hours in duration and were led by two child psychologists with experience in focus groups. A semi structured guide aided discussions and ensured they were theory driven. An inductive approach was used to analyse transcripts, using grounded theory methods to allow themes to emerge independent of theory.
Themes	Parents that tried to consistently adhere to medicate did so because they felt the improvements extended beyond just ADHD symptoms, and led to

Study (ref id)	Coletti 2012³⁴
	functional improvements of mood, sleep, and social functioning.
	For some parents, behavioural improvements outweighed side effects, and so they adhered to treatment.
Limitations and applicability of evidence	Minor limitations of the evidence

Study (ref id)	Gallichan 2008⁶⁰
Aim	Explore young peoples' perspectives of ADHD
Population	12 young people with ADHD (aged 10 to 17 years)
Setting	UK
Study design	Qualitative (interviews)
Methods and analysis	One on one open-ended interviews ranged from 25 minutes to 1 hour and 15 minutes. Grounded theory was used to analyse the data.
Themes	<p>Young people reported understanding why they needed to take their medication as they got older</p> <p>Children reported attempting to not take their medication and hide this from parents.</p>
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Ibrahim 2016⁸⁸
Aim	Examine the experiences of drug holidays from caregivers and healthcare professionals
Population	8 GPs, 8 consultants, 5 teachers and 5 mothers (aged children and young people)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews were carried out by one author using an interview schedule that focused on descriptions of ADHD and referral and diagnosis processes, and experiences with ADHD. Data was analysed using grounded theory.
Themes	Some parents could cope with their child not taking medication out of school hours, and felt it important to do so. However other parents' were unequipped to do this Young people want to stop their medication to feel like themselves and because they don't feel like the medication is helping
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Lefler 2016¹¹¹
Aim	To explore the experiences of college students living with ADHD
Population	36 college students with ADHD (aged >18 years)
Setting	USA
Study design	Focus groups
Methods and analysis	8 2 to 2.5 hour focus groups were conducted, each with 4-5 students. A semi-structured interview schedule was used. Focus groups were facilitated by either a clinical psychologist or a student training to be a clinical psychologist. Idiographic inductive analysis was used.

Study (ref id)	Lefler 2016¹¹¹
Themes	Students took medication holidays at their own direction, such as on the days that they had classes. Some students reported that they would also use more than was prescribed during periods of deadlines and examinations. They also reported frequently breaking pills up to take smaller doses than prescribed
Limitations and applicability of evidence	Minor limitations of the study related to a lack of context provided

Study (ref id)	Matheson 2013¹²⁵
Aim	Explore adults experiences with ADHD
Population	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)
Setting	UK
Study design	Interviews
Methods and analysis	Semi structured face to face interviews were conducted in the participant's home, or at the school of Pharmacy in London. An interview guide was used. Length approximately 1 hour. Thematic analysis used
Themes	<p>Patients reported only taking medication when it was required for work or education purposes</p> <p>Participants reported difficulty in accessing prescriptions, with GPs unwilling to prescribe or pharmacists reluctant to stock or dispense the medication.</p> <p>Participants reported that a lack of cooperation from pharmacists, GPs, and health trusts resulted in periods of cessation, which lasted from days to years. These periods were distressing for patients</p> <p>Many found delays in referral to adult services, discontinuation of support and medication upon turning 18</p> <p>Forgetfulness, side effects, uncertainty of effectiveness and a sense of lost identity were reported as the main reasons for treatment cessation</p>

Study (ref id)	Matheson 2013¹²⁵
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Meaux 2006¹³³
Aim	To gain insight about medication use among young people with ADHD
Population	15 college students with ADHD (aged 18+)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted by the principal investigator. Initial interviews lasted from 1 to 1.5 hours and follow up interviews lasted between 15 to 30 minutes. Content analysis was used to identify raw data clusters within the coded data. Raw data clusters were then combined to form themes
Themes	<p>Students reported they often forgot to take their medication</p> <p>Many students reported not taking their medication on the weekend when they were younger because they didn't want to 'feel like that' over the weekend</p> <p>Students reported that they not only take their medication when they need to, which generally was just when they had a large workload.</p>
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

Study (ref id)	Meaux 2009¹³²
Aim	Explore college students experiences of ADHD
Population	15 college students with ADHD (aged 18 to 21 years)

Study (ref id)	Meaux 2009¹³²
Setting	USA
Study design	Interviews
Methods and analysis	Semi structured interviews lasting 60 to 90 minutes were conducted. An interview guide was used . Content analysis was used to identify clusters of raw data, which were compared and combined to identify themes. Thematic analysis then allowed for further identification of themes.
Themes	Most participants were not taking their medication on a regular basis as they didn't like how the side effects made them feel.
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

Study (ref id)	Mills 2011¹³⁵
Aim	To understand how parents decide to medicate their child
Population	19 families (representing 30 children with ADHD) (aged Not specified)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted. Transcripts were analysed using constant comparative analysis, in order to generate conceptual categories and their properties. Open coding was used initially, followed by axial coding to connect the categories. No further details
Themes	The decision to keep a child on their medication was related mainly to the effectiveness of the treatment.
Limitations and applicability of evidence	Minor limitations related to the context of the study

Study (ref id)	O'Callaghan 2014¹⁴⁴
Aim	To explore the context that influences stimulant medication adherence

Study (ref id)	O'Callaghan 2014¹⁴⁴
Population	18 adults with ADHD (aged >18 years)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured telephone interviews lasted an average of 45 minutes. Notes were manually recorded and transcriptions analysed using thematic analysis.
Themes	Participants did not feel equipped to successfully stick to their treatment plan. This was due to being unable to keep monthly appointments for medication management. It seemed that those that benefited more from the treatment were more likely to adhere to it, with benefits clearly outweighing the harm of treatment. Participants reported difficulty getting a prescription refilled due to suspicious questions asked by pharmacists
Limitations and applicability of evidence	Severe limitations relating to the richness of data, data analysis, data collection and the role of the researcher

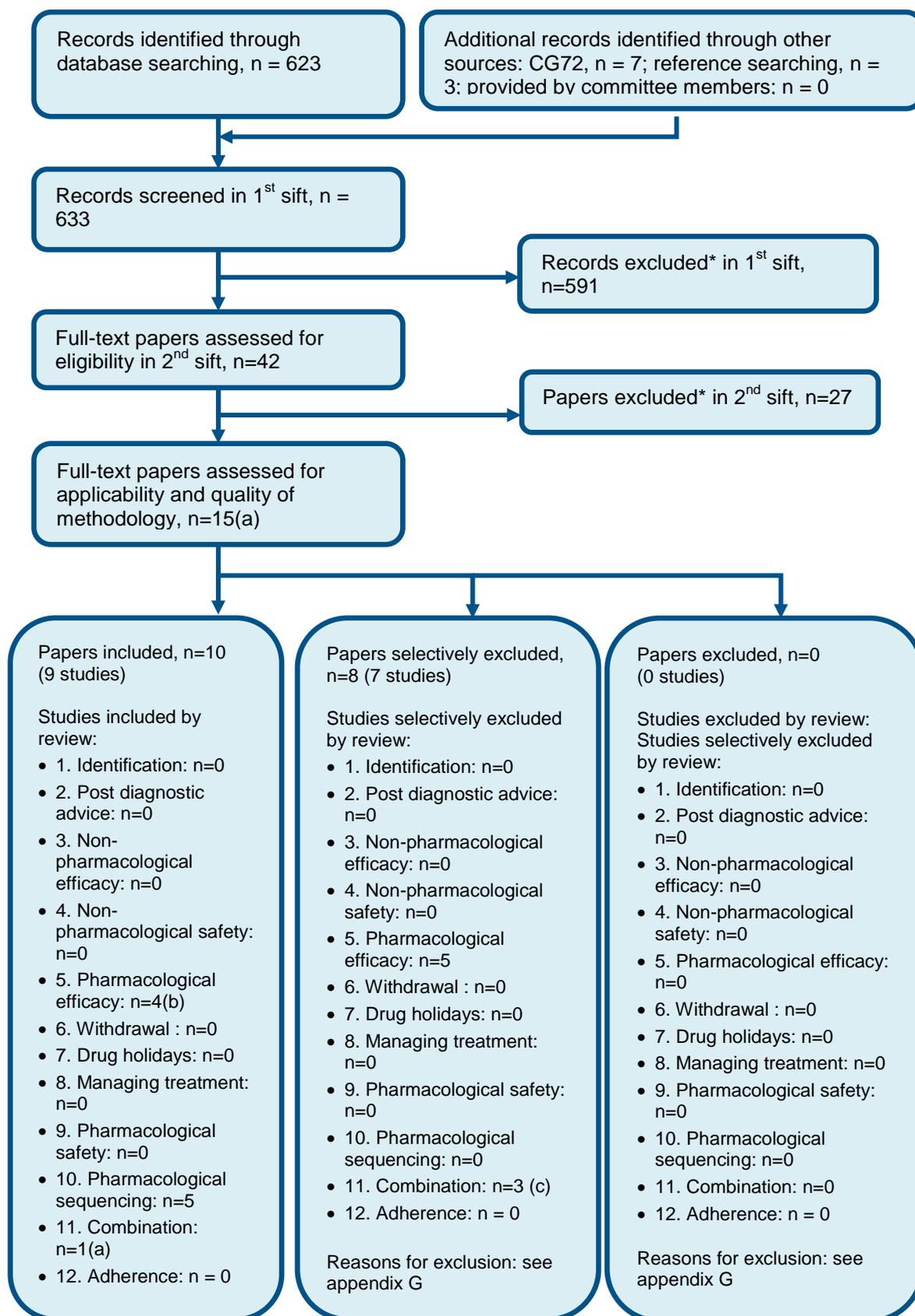
Study (ref id)	Sikirica 2014¹⁶⁴
Aim	To explore the unmet needs of young people with ADHD and their caregivers
Population	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years) with ADHD took part (aged 6 to 17 years)
Setting	Mixed European countries (including the UK)
Study design	Interviews
Methods and analysis	One to one telephone interviews were conducted by experienced interviewers, who took part in a training seminar including mock interviews. Each interview followed a standardised semi structured interview guide with open ended questions. Interviews with caregivers lasted between 60 to 90 minutes and interviews with young people lasted from 30 to 60 minutes. Thematic analysis was used to identify themes; an initial code system was developed which were organised into themes.
Themes	Participants reported allowing their children to deviate from their treatment and take breaks from their medication.
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Smith 2014¹⁷¹
Aim	Understanding the reasons of low uptake and completion of parent interventions for ADHD
Population	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (Pre-schoolers)
Setting	UK
Study design	Focus groups
Methods and analysis	semi-structured focus groups using an interview schedule based on themes for a qualitative literature synthesis. Analysed using thematic analysis
Themes	<p>Parents were more likely to drop out if they did not see improvement they expected quickly enough.</p> <p>Many barriers for patients in accessing non-pharmacological treatment were reported by parents and healthcare professionals. Psychological barriers included feelings of shame, embarrassment and fear of being judged. Situational barriers included time commitments, inconvenient session times and location and child care issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and financial difficulties impacted on adherence.</p>
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Swift 2013¹⁷⁸
Aim	Patient experiences of ADHD, particularly around transitioning services
Population	10 young adults with ADHD (aged 17-18)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews analysed by thematic analysis. Parents were allowed to be present during the interviews. Set questions were used during the interviews, but the format was flexible
Themes	Patients reported that their parents or other family members were often involved in support, helping with medication and clinic

Study (ref id)	Swift 2013¹⁷⁸
	appointments, where some people with ADHD struggle
Limitations and applicability of evidence	Minor limitations related to the richness of the data

1 **Appendix E: Health economic evidence**
2 **study selection**



* Non-relevant population, intervention, comparison, design or setting; non-English language

(a) note that there were 2 original models from the previous guideline (either included or excluded) which is why the numbers add to more than 15.

(b) Two articles identified were applicable to Q5 and Q10, for the purposes of this diagram it has been included under Q5 only.

(c) One of these is a model from the previous guideline that was exclude. Two articles identified were applicable to both Q5 and Q11 and have only been included here under Q11. One paper here was selectively excluded in Q11 but included in Q5 and so is double counted in this flowchart.

Appendix F: **Health economic evidence tables**

None.

Appendix G: Excluded studies

G.1 Excluded qualitative studies

Table 21: Studies excluded from the qualitative review

Reference	Reason for exclusion
Ahmed 2006 ²	No relevant themes
Ahmed 2013 ³	Systematic review
Andrews 2015 ¹⁹²	Incorrect study design
Ansari 2016 ⁴	Survey
Arango 2013 ⁵	Article
Bachman 2000 ⁶	Survey
Ball 2001 ⁷	Survey
Bartlett 2010 ⁸	No relevant themes
Bekle 2004 ⁹	Survey
Berger 2008 ¹⁰	Survey
Berger 2015 ¹¹	No relevant themes
Bringewatt 2013 ¹²	No relevant themes
Brinkman 2011 ¹³	Literature review
Brinkman 2012 ¹⁵	No relevant themes
Brodin 2008 ¹⁶	No relevant themes
Brook 2000 ¹⁸	Survey
Brook 2005 ¹⁷	Incorrect study design
Brown 2010 ¹⁹	No relevant themes
Bussing 1998 ²²	Survey
Bussing 2012 ²⁰	Survey
Bussing 2016 ²¹	Survey
Butler 2015 ²³	Systematic review
Canela 2017 ²⁴	No relevant themes
Carpenter-Song 2010 ²⁵	Article
Carter 2005 ²⁶	Survey
Charach 2008 ²⁸	Incorrect study design
Cheung 2015 ³⁰	No relevant themes
Clarke 2012 ³²	Incorrect study design
Clarke 2013 ³¹	Incorrect population
Clay 2008 ³³	Wrong population
Cooper 1998 ³⁵	No relevant themes
Corcoran 2016 ³⁶	Systematic review
Cormier 2012 ³⁷	No relevant themes
Couture 2003 ³⁸	Questionnaire
Darredeau 2007 ³⁹	Survey
Davis-Berman 2010 ⁴⁰	No relevant themes
Davis-Berman 2012 ⁴¹	No relevant themes
Deane 2012 ⁴²	Incorrect population
Dennis 2008 ⁴³	Literature review

Reference	Reason for exclusion
dosReis 2007 ⁴⁶	No relevant themes
Dosreis 2008 ⁴⁷	Incorrect study design
dosReis 2009 ⁴⁵	No relevant themes
dosReis 2010 ⁴⁴	No relevant themes
Edwards 2013 ⁴⁸	Wrong population
Einarsdottir 2008 ⁴⁹	No relevant themes
Eisenberg 2007 ⁵⁰	Survey
Elias 2017 ⁵¹	Incorrect population
Emilsson 2016 ⁵²	Survey
Faber 2006 ⁵³	Incorrect study design
Fiks 2010 ⁵⁴	No relevant themes
Firmin 2009 ⁵⁵	No relevant themes
Flannagan 2002 ⁵⁶	No relevant themes
Fleishcman 2013 ⁵⁷	Survey
Frank 2015 ⁵⁸	Incorrect study design
Friars 2009 ⁵⁹	No relevant themes
Garro 2009 ⁶¹	Article
Gau 2009 ⁶²	Incorrect study design
Gerdes 2014 ⁶³	Incorrect study design - questionnaire
Ghanizadeh 2010 ⁶⁴	Questionnaire
Ghosh 2016 ⁶⁵	No relevant themes
Ginsberg 2008 ⁶⁶	Incorrect study design
Goodwillie 2014 ⁶⁷	No relevant themes
Gwernan-Jones 2015 ⁶⁹	Literature review
Gwernan-Jones 2016 ⁶⁸	Systematic review
Hack 2001 ⁷⁰	Incorrect study design
Hallberg 2008 ⁷¹	No relevant themes
Hallerod 2015 ⁷³	No relevant themes
Hansen 2006 ⁷²	No relevant themes
Harazni 2016 ⁷⁴	No relevant themes
Harvey 2009 ⁷⁶	Wrong population, incorrect study design
Hassink-Franke 2016 ⁷⁷	No relevant themes
Hazell 2004 ⁷⁸	No qualitative results reported
Hebert 2013 ⁷⁹	Survey
Henry 2011 ⁸⁰	No relevant themes
Hill 2016 ⁸¹	Survey
Ho 2011 ¹⁸⁹	No relevant themes
Hong 2008 ⁸³	No relevant themes
Honkasilta 2014 ⁸⁴	No relevant themes
Honkasilta 2016 ⁸⁵	No relevant themes
Hughes 2007 ⁸⁶	No relevant themes
Hughes 2009 ⁸⁷	No relevant themes
Ide-Okochi 1016 ⁸⁹	Article
Jackson 2008 ⁹⁰	No relevant themes
Kean 2005 ⁹¹	Incorrect study design

Reference	Reason for exclusion
Kendall 1997 ⁹²	Incorrect study design
Kendall 2003 ⁹³	No relevant themes
Kendall 2016 ⁹⁴	No relevant themes
Kildea 2011 ⁹⁵	No relevant themes
King 2016 ⁹⁶	Wrong population
Kisely ⁹⁷	Survey
Klasen ⁹⁸	No relevant themes
Knipp ⁹⁹	No relevant themes
Ko ¹⁰⁰	Questionnaire
Koerting ¹⁰¹	Review
Kollins ¹⁰²	Review
Kovshoff ¹⁰⁴	No relevant themes
Kronenberg ¹⁰⁵	Incorrect population
Kutuk 2016 ¹⁰⁶	Survey
Larson ¹⁰⁷	No relevant themes
Laugesen ¹⁰⁸	Unable to access
Laugesen ¹⁰⁸	Systematic review
Lee ¹⁰⁹	No relevant themes
Lee ¹¹⁰	No relevant themes
Leggett ¹¹²	No relevant themes
Leslie ¹¹³	No relevant themes
Lewis 2016 ¹¹⁶	Erratum
Lewis-Morton ¹¹⁴	No relevant themes
Liebrez 2016 ¹¹⁷	No relevant themes
Lin ¹¹⁸	No relevant themes
Ljusberg ¹¹⁹	No relevant themes
Loe ¹²⁰	No relevant themes
Lopes ¹²¹	Incorrect population
Maassen ¹²²	No relevant themes
Marcer ¹²³	Questionnaire
Mathers ¹²⁴	Incorrect study design
Matthys ¹²⁶	No relevant themes
McCarthy ¹²⁷	Survey
McGoron ¹²⁸	Questionnaire
McIntrye ¹²⁹	No relevant themes
McKay ¹³⁰	Wrong population
McMenamy ¹³¹	Wrong population
Michielsen ¹³⁴	Wrong population
Mills ¹⁰³	Abstract
Moen ¹³⁶	No relevant themes
Morsink 2017 ¹³⁷	No relevant themes
Muhlbacher ¹³⁸	Abstract
Muhlbacher ¹³⁸	Abstract
Murrell ¹³⁹	Incorrect study design
Mychailyszyn ¹⁴⁰	No relevant themes

Reference	Reason for exclusion
Myers ¹⁴¹	Incorrect study design
Nehlin ¹⁴³	No relevant themes
Olaniyan ¹⁴⁵	No relevant themes
Oruche ¹⁴⁶	Wrong population
Perry ¹⁴⁷	No relevant themes
Ramsay ¹⁴⁸	Incorrect study design
Raskind ¹⁴⁹	Survey
Reale ¹⁵⁰	Survey
Reid ¹⁵¹	No relevant themes
Rogalin ¹⁵²	No relevant themes
Russell ¹⁵³	No relevant themes
Salt ¹⁵⁴	No relevant themes
Sandler ¹⁵⁵	No relevant themes
Schatz ¹⁵⁶	Systematic review
Schreuer 2017 ¹⁵⁷	No relevant themes
Schrevel ¹⁵⁸	No relevant themes
Schrevel ¹⁵⁸	No relevant themes
Schubert ¹⁵⁹	No relevant themes
Segal ¹⁶⁰	No relevant themes
Segal ¹⁶¹	No relevant themes
Shattell ¹⁶²	No relevant themes
Shaw ¹⁶³	No relevant themes
Simons ¹⁶⁵	No relevant themes
Singh ¹⁶⁷	Article
Singh ¹⁶⁶	No relevant themes
Singh ¹⁶⁸	Article
Singh ¹⁶⁹	Article
Sleath 2016 ¹⁷⁰	Survey
Soderqvist 2017 ¹⁷²	No relevant themes
Solberg ¹⁷³	Incorrect study design - questionnaire
Sox ¹⁷⁴	Incorrect study design
Srignanasoundari 2017 ¹⁷⁵	No relevant themes
Stroh ¹⁷⁶	Survey
Surman ¹⁷⁷	Incorrect study design
Tatlow-Golden 2016 ¹⁷⁹	Systematic review
Taylor ¹⁸¹	No relevant themes
Taylor 2015 ^{180 180}	No relevant themes
Thiruchelvam ¹⁸²	Incorrect study design
Travell ¹⁸³	Analysis
Varley ¹⁸⁴	Article
Waite ¹⁸⁵	No relevant themes
Wallace ¹⁸⁶	No relevant themes
Wan 2016 ¹⁸⁷	No relevant themes
Wiener ¹⁸⁸	No relevant themes
Wilkes-Gillan ⁸²	No relevant themes (parental intervention)

Reference	Reason for exclusion
Wilkinson ¹⁹⁰	No relevant themes
Williams ¹⁹¹	No relevant themes
Williamson ¹⁹³	Incorrect study design
Winter ¹⁹⁴	Incorrect study design
Wolpert ⁷⁵	No relevant themes
Wright ¹⁹⁵	No relevant themes
Young ¹⁹⁷	No relevant themes
Young ¹⁹⁶	No relevant themes
Young ¹⁹⁸	No relevant themes
Zhang 1017 ¹⁹⁹	No relevant themes

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Table 22: Studies identified but not included in the qualitative review due to saturation being reached

Reference
Lewis 2016 ¹¹⁵

5

G.2 Excluded health economic studies

6

None.